

Conflict of Interest in Case Management
Comments from Green Mountain Self-Advocates

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General Comments

Making sure we get services that help us get the life we want is complicated.

GMSA is pleased that the federal government made rules saying people who get services must be able to make everyday choices for themselves like:

- what we do every day
- who we talk to
- what kinds of relationships we have
- where we spend our time.

The federal rules say providers can't just offer only a few options for community support (like going swimming or walking on a bike path). We can't be limited to only going out with staff from 9 to 3 on weekdays. The rules say we must have the same kinds of choices and freedoms that people without disabilities typically have. We should have the support we need to change our minds and do something on the spur of the moment, just like everyone else.

GMSA has a training for support workers called *Look Through Our Eyes*. The message is about how to help us get lives where we have control. Creating a life where we define what quality of life looks like. Michael Smull, chair of The Learning Community for Person Centered Practices said, "Working in a person-

centered way requires that we see the person first – what matters to them, not just what the matter is with them.”

When it comes to making decisions, this is where it gets tricky because most of us need help. So, the person who helps us make decisions must be:

- Neutral
- They should not be someone with a whole lot of rules and opinions in their head about what we can and cannot do.
- They need to listen to us
- They cannot have their own agenda
- It needs to be somebody who is not getting in our heads

Feedback on DAIL's Options

Ombudsman

For years GMSA has been strongly saying we need an ombudsman for Developmental Services. Self-advocates like the idea of having someone on the outside of an agency to contact. It would be a safer way to say what problems they are having with an agency. Today, when a person or their staff complain to the higher-ups at an agency they often feel negative tension and are reluctant to speak up.

But an ombudsman is just part of the solution. Most people who get services do not have the ability to call on their own. We still need other outside people looking in on our lives to make sure our lives are going in a direction we want to go.

Peers Listening To Us, Telling Us About Options And Finding Out What We Really Want To Do

GMSA supports using peer options to lessen conflicts of interest in case management. We need people to listen. We need to hear about our options from a neutral person. GMSA can train and support peers to help peers plan and make decisions. What a great opportunity.

This would put the peer to peer connections to work. Having an individual with a disability as the person listening and explaining options to another individual with disabilities would be very reliable. Having people who have similar, or almost identical, challenges with services there to assist would be valuable. We need reliable information. We need to know all the options. The information should not be sugar-coated.

Self-advocates have said that it would be helpful to have a peer work with them to prepare for their ISA meetings. Some feel it would be beneficial to have peers with them during ISA meetings. Having a peer can help us speak up during our meetings. They can help us get meetings back on track when they drift away from what is important to us. The atmosphere feels safer when you have another peer with you.

Other states have trained self-advocates to teach workshops to their peers about person-centered planning and to facilitate planning sessions. At the very least independent case managers should be teamed up with peer advocates when doing assessments, overseeing planning and checking on quality of services.

Setting Up Independent Case Managers

GMSA agrees with the option that the state should be responsible for setting up independent case managers that operate outside of the agency. We see conflict of interest problems with the option of the agencies being responsible for establishing independent case managers.

Today people already have the option of self-managing their services or switching to a different agency. GMSA often encounters self-advocates and their families who are unaware of these options. Relying on designated agencies to promote these options is not working. It seems unfair to ask agencies to be the only ones responsible for promoting other service options which may result in them losing funds. It is natural for agency staff to want to keep working with a person. It is hard for them to suggest that a person leave and get their services somewhere else.

Planning

Self-advocates told us they want people who know them to help them with their ISAs. But people also said it is equally important to be in charge of our services. We need a person outside of the agency to listen to what we want in our lives. Someone knowledgeable about all the different options.

GMSA strongly believes that the focus should be towards what individuals want directly from their point of view, not someone else's. So, zero in on what is important **TO** the person, in addition to what is important **FOR** a person. Agencies and families are good at knowing what is important **FOR** a person. It takes a lot of hard listening and trying things out to find out what a person prefers especially if they have only a few ways to communicate. We need people on the outside

looking in to make sure individuals are truly being heard. This is a way to know that we are being taken seriously and listened to directly.

Problems With The Way The State Is Gathering Feedback

GMSA has been talking about conflicts of interest in case management for more than a year. We've done many presentations for our local self-advocacy groups and for our board with representatives from across Vermont. Here are our concerns about the way information is being shared:

- There is a lot of confusion.
- The discussions are fast paced. The words are too complicated.
- DAIL uses the same word when referring to independent case managers working outside of an agency and the existing case managers working for an agency. Please don't. For the entire time people have received services the word case manager has had a specific meaning associated with a person working for an agency. You can't just simply give the word a new meaning and expect people to understand. People are very confused, and most of the confusion comes from using the same word for two different things.
- DAIL says it is their job to figure out how to pay for the new system. This is misleading. It is going to cost a lot of money to set up a new system. Some legislators have clearly said they will not be providing funding to pay for all the additional costs. Please be honest. It appears the change will come out of people's services which means they will get less services.
- The charts evaluating the different options were too confusing. We need concrete examples of how it will work.

- There needs to be more opportunities for self-advocates to share their concerns in private settings. People are reluctant to say how controlled they feel by their agency staff and family members.

A Few Examples Of Conflicts of Interests in Case Management

- Some people who get services live rich and fulfilling lives. However, many people spend their days doing the same rudimentary kind of stuff. They have few relationships with people who are not paid to be with them.
- People are spending more time in segregated settings. There is a lack of creativity to build options around a person's interests. Support staff tend to lack the skills needed to support a person to establish natural supports in their communities.
- There are many people who have complaints about their services. These complaints have been ongoing and there is not a sense that it will change. People said they feel like there is nowhere to go to get it resolved.
- Doubling-up often is a problem. People complain they have to do what the other person wants. Some people said they could initially choose who they were paired up with. But, we heard that at least at one agency, if it did not work out, people were stuck with that arrangement for the rest of the year.
- Many people if asked will say they want a girlfriend or boyfriend. But most people are not provided with the education and support they need to date.
- A big issue is the lack of staff. If our staff person is out often we go without. There is nothing we can do about it.
- People are not getting enough support to speak up when being silenced by their families.

- Some people said their service coordinator was with them for several years and they were like a sister. Others described being bounced around to different service coordinators all the time (i.e. 3 in 2 years, 4 in 5 years).
- At DAIL forums we heard parents say they were able to keep an eye on things when their son or daughter was in between case managers. But what about all the people who do not have contact with their families, or they feel controlled by their families. Who is watching out for them?

Thank you for considering our concerns.

Green Mountain Self-Advocates

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